

# Health Advocate

E-Newsletter of the National Health Law Program

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## Autism Spectrum Disorders

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### Key Resources

[NHeLP Q&A: CMS Guidance on EPSDT Services for Children with ASD in Medicaid](#)

[NHeLP Lessons from California: Covering Behavioral Health Treatment in Medi-Cal](#)

[Autism Speaks – ASD and Medicaid](#)

[CMS on ASD and Medicaid](#)

[CMS EPSDT Coverage Guide](#)

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**Coming in November's  
Health Advocate:**

**Reproductive Health:  
Data Project Round-Up**

### Introduction

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate of the Medicaid Act requires states to cover a wide variety of health services to correct or ameliorate the illnesses or conditions of children under age 21 in Medicaid. As new treatments and services are developed and incorporated into the standard of care for treating children's illnesses and conditions, the Centers for Medicare & Medicaid Services (CMS) has struggled to ensure that state EPSDT programs keep up with the evolving standard of care for children.

A recent example involves behavioral treatments for Autism Spectrum Disorder (ASD), a developmental disability that can cause significant delays in social, communication, and other behavioral skills. The standard of care for children with ASD for many years has included intensive behavioral interventions such as Applied Behavioral Analysis (ABA) therapy. ABA therapy is based on a one-on-one teaching approach that relies on reinforced practice of various skills. Yet states have been slow to cover these interventions under their Medicaid programs, and CMS had also not required states to cover them until last year. Due in part to NHeLP's advocacy, in July 2014, CMS issued a *Clarification of Medicaid Coverage of Services to Children with Autism (ASD CMS Guidance)*, which made clear that states must provide evidence-based treatments for children with ASD in Medicaid. This month's *Health Advocate* reviews the advocacy history that led up to this guidance, and then examines trends in the states' implementation of the guidance.

### Treatment for Autism Spectrum Disorders

The CDC recently estimated that approximately one in every 68 children has been identified with ASD. (CDC, [Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years](#) (2014).) Since the 1980s, intensive behavioral interventions have become increasingly used to treat children with ASD by assisting them in building skills and reducing maladaptive behaviors. ABA therapy is perhaps the best-known of these therapies. ABA therapy is based on a one-on-one teaching approach that relies on reinforced practice of various skills. ABA therapy is typically provided by certified therapists and a team of behavior technicians, pursuant to a referral from a licensed practitioner such as a neurologist or psychologist. Although state laws are beginning to change, in most states, the therapists and paraprofessional staff who administer ABA therapy, though certified by a national board, are not licensed under state law. While ABA therapy is particularly well-known, many individuals with ASD receive other evidence-

based intensive behavioral interventions. These interventions may be as effective, or even more effective, for some children with ASD, depending on their individual needs. Together, this cohort of intensive behavioral interventions constitutes the standard of care for in treatment for children with ASD.

## CMS Issued Guidance on Treatment for ASD in Medicaid Under EPSDT

Since the late 1990s through the 2000s, advocates began to push their states to provide intensive behavioral interventions for ASD in Medicaid. For several years advocates around the country—including NHeLP—have argued that for children with ASD, ABA therapy and other intensive behavioral interventions for ASD must be covered under EPSDT, since they have been shown to be effective treatments at correcting and ameliorating ASD. But many states considered these intensive behavioral interventions to be “habilitative” services aimed at acquiring new skills rather than restoring or preventing deterioration of an existing condition. States are not required to cover habilitative services under EPSDT. As such, many states only provided ABA therapy and other intensive behavioral interventions through a Medicaid waiver home and community-based waiver programs, which may limit the number of children who can get the services and how much of the services they can get.<sup>1</sup> Therefore, not all children with ASD in Medicaid were able to access treatments they need. In the late 2000s, families in Florida, Louisiana, Ohio, and Washington successfully sued their states to obtain coverage of intensive behavioral interventions in Medicaid pursuant to the EPSDT mandate. Moreover, in the months before releasing its July 2014 Guidance, CMS approved requests by Louisiana and Washington to cover ABA therapy under EPSDT.<sup>2</sup>

NHeLP and other advocates asked CMS to clarify that states must provide evidence-based treatments for children with ASD, including intensive behavioral interventions, under EPSDT. In July 2014, CMS responded to these requests by releasing guidance that explained that states are obligated to cover these services for children under age 21 when they are medically necessary, even if they are not covered for adults in Medicaid. In September 2014, CMS issued an [FAQ](#), further explaining states’ obligation to cover services for children with ASD under EPSDT. The FAQ stated that CMS would be working with states to update and expand the menu of services available to children with ASD. It clarified that CMS would require states that previously only offered intensive behavioral interventions for children with ASD through a Medicaid waiver to transition provision of those services to regular Medicaid program. CMS declined to set a particular deadline by which states must come into compliance with its guidance, but indicated that states should “work expeditiously and should not delay or deny provision of medically necessary services.”

## State Activity to Provide Treatment for ASD in Medicaid in the Last Year

Following up on last year’s guidance and FAQ, NHeLP and other advocates quickly began working with states to add intensive behavioral interventions for children with ASD to their state Medicaid programs under EPSDT. Our research suggests that as of September, 2015, 24 states and the District of Columbia are already offering intensive behavioral interventions to children with ASD in their regular Medicaid programs. Following the plans CMS approved last spring for Washington and Louisiana, the agency has approved requests (through state plan amendments) in three additional states to include intensive behavioral interventions for children with ASD in their Medicaid programs.

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<sup>1</sup> Home and community-based waiver programs allow states to provide long-term care services in home and community-based settings under the Medicaid Program. Programs can provide a combination of standard medical services and non-medical services. But states can also place limits in these programs that would not be allowed in their regular Medicaid programs. (See [CMS, 1915\(c\) Home and Community Based Waivers](#).)

<sup>2</sup> Each state must submit a state Medicaid plan to CMS that sets forth, among other things, the benefits that the state covers in its Medicaid program. When a state changes the benefits offered in its Medicaid program, it generally must submit a proposal, called a “state plan amendment,” to CMS for approval.

Several other states have submitted state plan amendments to CMS proposing to add intensive behavioral interventions to their Medicaid programs (and many of those states have already begun providing services while CMS reviews their proposals). Other states had existing language in their state Medicaid plan that permitted them to offer intensive behavioral interventions without submitting a state plan amendment to CMS. Some states are still in the very early planning stages of crafting a state plan amendment or other policy documents to make intensive behavioral interventions available in their Medicaid programs. Some states have not yet taken any steps to implement the guidance.

## Next Steps

While nearly half of states are working to implement CMS's guidance on services for children with ASD under EPSDT, 25 states have yet to make significant headway. NHeLP is working with advocates in those states to push their states and CMS to ensure that children with ASD gain access to the full scope of services to which they are legally entitled.

Even among the states that have already begun providing intensive behavioral interventions to children with ASD, we are seeing some common themes that can create barriers to care. In many states, advocates report the reimbursement rates for intensive behavioral interventions are very low. As a result, those state Medicaid programs struggle to attract enough trained, quality providers to meet the state's need. Another common problem is that some states place hard limits on the hours of service Medicaid will provide in a week or a month. These limits, which are illegal under EPSDT, prevent children with the highest need from getting all of the medically necessary care to which they are entitled. (*See* CMS, [EPSDT Coverage Guide](#) at 23.) Another common problem is state refusal to provide services to children during the school day. Such limitations violate EPSDT and can prevent children who experience the most severe symptoms of their ASD at school from receiving adequate treatment. *See* 42 U.S.C. § 1396b(c). NHeLP is working with advocates around the country to address these and other barriers to care under EPSDT. We encourage advocates to work with CMS and their states to ensure that intensive behavioral interventions for children with ASD are available through Medicaid whenever they are needed.

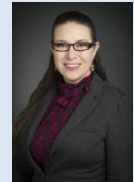
## About Us

The National Health Law Program protects and advances the health rights of low income and underserved individuals. NHeLP advocates, educates and litigates at the federal and state level.

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